

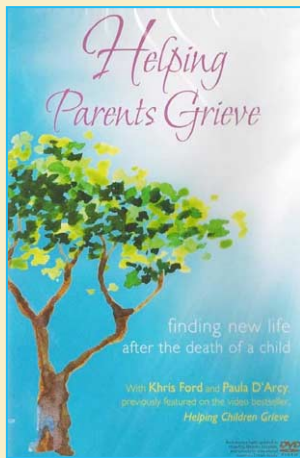


family @ linkages

NEWSLETTER

A way to connect families of children and youth with special needs in Michigan
with information, education and support

Remembering, Supporting, and Encouraging in the Month of July



Often we don't know what to say or do for grieving parents, so we may turn away and do nothing.

The month of July is designated as **Bereaved Parents Awareness Month**, a time for supporting our friends and loved ones who've experienced the loss of a child. Begin to turn back. Reach out to families who are grieving by giving them someone who will listen without advising; a shoulder to cry on; and a hug when appropriate and needed. Basically, "be there."

Join various health professionals, friends, and family members embrace, support and encourage parents after the death of a child and bring awareness to parent bereavement.

For helpful material, visit: www.BereavedParentsAwarenessMonth.info and <http://www.compassionatefriends.org/resources.aspx> or contact the Family Phone Line at (800) 359-3722.

Mothers who wish to socially network with other moms who have experienced a loss can join: <http://www.facebook.com/pages/Grieving-Mothers/122565794442974>.

Fathers can join: <http://www.facebook.com/grievingfather> to connect with other dads.

Remember to reach out to the bereaved so they won't have to grieve alone!

July 28 is WORLD HEPATITIS DAY

July 28 has been chosen as World Hepatitis Day by the World Health Organization (WHO), in order to raise awareness of viral hepatitis and how to prevent it. Hepatitis is caused by a virus that infects the liver. The most common forms of hepatitis are A, B and C. There are safe vaccines to protect against Hepatitis A and B.

Get your child the vaccine to protect him or her against this disease. If your child does not have health insurance, or does not have insurance that covers these vaccines, ask your health care provider or local health department about the Vaccines for Children (VFC) program. This program provides no- or low-cost vaccines to eligible children, 18 and younger.

For more information, talk to your child's doctor, call 800-CDC-INFO (800-232-4636), or visit the following websites:

- www.cdc.gov/hepatitis
- www.cdc.gov/vaccines/parents/index.html



July is Wheelchair Beautification Month

It all began when illustrator and wheelchair-user Horace Knowles suggested attaching fresh flowers to the top of his wheelchair to brighten his day and bring a smile to everyone he passed.

To celebrate Wheelchair Beautification Month, have a wheelchair decorating contest. Decide on a theme. Provide the decorating supplies, e.g., ribbon, flowers, streamers, Mylar balloons and helium, colored poster board, long feathers, fabric, glue sticks, string, glitter, etc. Encourage theme development, e.g., Bat-mobile, covered wagon, Model-T, limo, etc.

Encourage other families to help loved ones decorate their wheelchairs. Involve siblings and friends. Organize a “parade” through the park, neighborhood or around the block to show off the creativity to the community. Publicize the event and take lots of pictures. Post your event on Facebook.

This is a great opportunity to allow children and youth who are wheelchair users to personalize and show off their individual style. It is also a good time to have volunteers make new wheelchair bags.



Juvenile arthritis (JA) refers to any form of arthritis or arthritis-related condition that develops in children or teenagers who are less than 18 years of age. Approximately 294,000 children under the age of 18 are affected by pediatric arthritis and rheumatologic conditions.

Recognizing the need for an organization that focuses specifically on juvenile arthritis, the Arthritis Foundation formed the American Juvenile Arthritis Organization (AJAO) in 1981 to advocate for and work to improve the quality of life for children with rheumatic diseases. For 31 years, AJAO created programs and services to help children and their families navigate the emotional diagnosis of juvenile arthritis, including hosting the AJAO conference every summer.

Bringing families of children with JA together from all over the country, the conference provides the latest information and gives children a chance to connect with other kids living with JA.

Nationwide, the Arthritis Foundation hosts thirty-five camps (including Michigan's Camp Dakota) designed especially for children living with arthritis. With medical staff on hand to care for campers, and activities designed so that all can participate, kids across the nation are learning that they can have fun with other children living with arthritis, all while sharing.

Camp Dakota runs from July 29, 2012 to August 3 2012. For questions contact Kara Dorda at (800) 968-3030 or kdorda@arthritis.org

The Arthritis Foundation, Michigan provides information about programs and services to families, opportunities for families to be involved in local programs and events, the Parent-to-Parent Network which links a parent of a child newly diagnosed with juvenile arthritis with an “experienced parent”; a Pen Pal Program; and medical volunteers to conduct “Kids Get Arthritis Too!” presentations for health care providers.

To learn more about Michigan services visit: <http://www.arthritis.org/michigan>.

The Michigan Department of Community Health Care Services (CSHCS) can provide financial assistance for medical expenses of children with arthritis. For more information about CSHCS contact the Family Phone Line at (800) 359-3722.





UV Protection and Eye Safety

When you or your children play outdoor sports or work outside, you should think about both UV protection and proper safety eyewear.

UV protection does not cost a lot of money and does not get in the way of seeing clearly. Sunglasses help you in two important ways. They filter light and they protect your eyes from damaging UV rays. Mounting evidence shows that exposure to UV rays can damage your eyes. Long-term exposure to UV rays can lead to cataracts, macular degeneration or skin cancer around the eyelids.

Children are at special risk from the harmful effects of UV rays, since their eyes do not have the same ability as adults to protect from UV radiation. Some helpful suggestions for choosing sunglasses for children are: check to make sure the sunglasses fit well and are not damaged; choose sunglasses that fit your child's lifestyle — the lenses should be impact resistant and should not pop out of the frames, and choose lenses that are large enough to shield the eyes from most angles. Find a wide-brimmed hat for your child to wear along with the sunglasses. This will give your child extra protection against the sun. Wearing a hat can cut the amount of UV rays that reach the eyes in half. Like adults, children should wear brimmed caps and sunglasses that screen out 99 to 100% of UV rays.

For more information about eye safety and eye injury prevention visit: <http://www.preventblindness.org/>



Cleft and craniofacial conditions affect thousands of infants, children, teens and adults in the United States each year. Some are born with congenital anomalies like cleft lip and palate, others with more complex, life-threatening craniofacial conditions. Some are burned; others are injured in accidents and animal attacks, or diagnosed with various oral/head/neck and skin diseases.

To learn more about these conditions, including treatment options and support networks in your area, call MICLEFT Toll Free: (888) MICLEFT, email: support@MiCleft.com or visit: <http://www.micleft.com>.



Will it hurt?

Most parents of young children know that often at the doctor's office you will have to face the dreaded shot! Fortunately, a developmental screening during your next well-child visit with your doctor is nothing to dread or fear.

What can you expect when your doctor does a developmental screening of your child?

A developmental screening done in a doctor's office is painless.

There are just a few simple steps:

1. You will answer some questions about what your child can do, such as walking, talking, feeding himself or herself, or sleeping all night long. Sometimes your doctor will give you the questions to fill out while you are at home with your child. But you will probably get the questions when you check-in for your appointment and you can answer them in the waiting room.
2. After you turn in the questions to the front desk, someone working in the office, usually a nurse or doctor, will score it.
3. Before your doctor comes into the exam room, he/she will look at the score and decide if there are any concerns to discuss with you. Be sure to bring up any concerns that you may have at this time.
4. Your doctor can do a screening at your child's 9-month, 18-month, and 24- or 30-month well-child visit. But if you have a concern any other time, be sure to talk about it with your doctor.

Next month look for the final article in our series, "Playing with Baby," to learn what happens after a developmental screening.

If you are a parent and would like more information on developmental screening, please visit www.cdc.gov/ncbddd/childdevelopment.

If you are a physician, and would like more information on training opportunities to learn to implement developmental screening contact Tiffany Kostelec at kostelect@michigan.gov.

PCDS is a project of the Michigan Department of Community Health in partnership with the Early Childhood Investment Corporation, the Michigan Chapter of the American Academy of Pediatrics, and the Michigan Academy of Family Physicians.



July is Cord Blood Awareness Month

Celebrate the birth of your baby. Protect your family. Plan for the future.

Modern medicine makes treatment possible for babies born with rare conditions like primary immune deficiency (PID), cancers and blood disorders. Babies with PID usually appear normal at birth. But their bodies cannot make working white cells. The white cells are the warrior cells. They float in the blood and fight germs.

Babies without working white cells can become sick very easily. But it is very hard for them to get well without warrior cells. One treatment for PID is cord blood transplant, also called hematopoietic stem cell transplant (HSCT). Cord blood is collected from the baby end of the cord and placenta right after birth. Cord blood stem cells can grow and develop into many different types of blood cells, like white blood cells, red blood cells and platelets.

The cord blood is screened for various infections before being frozen for future use. Cord blood from a well donor can make the difference between life and death for a baby with PID. The best match for a donor is often cord blood from a close relative. Having cord blood stored on every child means it is available if needed.

Plan ahead. Look into collection and storage of cord blood well before your baby's delivery date.

Find out more about MDCH Newborn Screening:
www.michigan.gov/newbornscreening

Read Michigan's Public Health Law on Cord Blood:
legislature.mi.gov/doc.aspx?mcl-333-2681

Learn more about cord blood:
parentsguidecordblood.org



WHITE AND RED BLOOD CELLS



2012 Summer Learning Webinar Series



Join Michigan Alliance for Families as we present a free series of webinars for parents, caregivers, and educators.

All are free and run on Thursdays from noon–1 PM.

Download the flyer at:

www.michiganallianceforfamilies.org/webinar/2012summerwebinars.pdf

or register at

www.michiganallianceforfamilies.org/webinar/index.htm

Questions? Email

info@michiganallianceforfamilies.org

July 12: Ask The Expert with advocate Kelly Orginski from Michigan Alliance for Families

July 19: Peer to Peer Support—the LINK Program with Maureen Ziegler from Statewide Autism Resources and Training Project (START)

July 26: Writing Effective Complaints with Mark McWilliams from Michigan Protection & Advocacy Service (MPAS)

August 2: Advocacy and Communication with Kelly Orginski from Michigan Alliance for Families

August 9: Visual Supports Strategies with Kelly Dunlap from Statewide Autism Resources and Training Project (START)

August 16: Assistive Technology Considerations with Laura Taylor from Michigan's Integrated Technology Services (MITS)

ANNUAL CONFERENCES

Family & Consumer Science Educators of Michigan

- August 01, 2012 – August 02, 2012

Bavarian Inn Lodge and Conference Center
One Covered Bridge Lane
Frankenmuth, MI 48734

For more information call: Louise Bombyk at (989) 288-2380

Family Support Network—Support Parent Training



- July 20-22, 2012

Peninsula Bay Inn

2603 N Lincoln Road, Escanaba, MI 49829

Lodging included, mileage and childcare reimbursed.

Onsite child care included (with prior registration). Space is limited to 25 registrants.

For more information, or to register call: Dianna at (800) 359-3722

Affordable Care Act Forums

What health insurance changes can families anticipate from the Affordable Care Act?

- July 30, 2012

1:00 PM – 3:00 PM

South Haven Memorial Library

314 Broadway, South, Haven, MI 48090

This two-hour session will offer practical, basic information about anticipated changes in accessing health insurance benefits, the requirement to buy health insurance (sometimes known as the “individual mandate”), who will be eligible for financial help to pay premiums, what will be covered through health insurance, and purchasing health insurance through an exchange.

In addition, we'll talk about Medicaid expansion under the Affordable Care Act and the issues currently being decided by the United States Supreme Court.

The Power Point presentation, handouts, and discussion are designed to supplement what you already know about this law. An interactive approach and conversation will be used to share information based on the needs of participants.

To attend this free session visit:

www.gifttool.com/registrar/ShowEvents?ID=1862&VER=1&LNG=EN

Making Every Minute Count

Using DEC's Recommended Practices to Embed Learning Opportunities in Everyday Routines

- August 9, 2012

9:00 AM to 4:00 PM

Clinton County RESA

1013 S US Highway 27 #A
St. Johns, MI 48879



For more information: call 406-543-0872 or send an email to dec@dec-sped.org

